

325 Sexuality in cystic fibrosis (CF) patients

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Background: Nowadays CF patients have a longer life expectancy, so they can meet usual adult life experiences. Sexual activity and procreation are areas of increasing interest for which they need to be taken into care.

Aim: This study evaluated specific aspects of sexual growth in CF patients.

Methods: An ad-hoc questionnaire realized by our team was addressed to CF patients (n=26) and to a control group (n=26). Data were processed descriptively and significance was assessed by χ^2 statistic test.

Results: Respondents' mean age was 32.6 yrs (12 men) for the CF group and 30 yrs (7 men) for the control group. Samples significantly differed (p=0.04) in the way they got very first information about sexuality: CF patients received less information from the family compared to the control group. Frequency of sexual activity was divided into real and ideal frequency rate and data showed that the ideal frequency was significantly lower in CF patients (p=0.0007). CF patients had a significantly lower pregnancy planning in comparison with the control sample (p=0.03).

Conclusions: These findings may suggest that the area of sexuality is not so felt as a vital and developmental area for a CF patient by parents with the risk of its underestimation along childhood. Thus it would be useful to support parents about these themes so these could be considered as part of their children global growth. It seems that this early-sexuality approach could last indeed, resulting in a lower self-investment compared to the healthy group and intra-patients. Further studies may look for any relation of these sexual variables (lower investment, projection and planning) with the health status of our patients.

327 Employment and education in adults with cystic fibrosis: employment experiences

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Background: Over the past few decades there has been a dramatic improvement in the survival and health of patients with cystic fibrosis (CF). The aim of this study was to investigate the impact of such change on employment within our cohort.

Methods: Patients completed a questionnaire covering education, employment history and perceptions of the impact of CF. Current lung function and BMI were recorded and socio-economic status calculated using postcodes. Individuals' perception of the impact of CF on employment was assessed using a 10 point scale. Non-parametric correlations and logistic regression were used for data analysis.

Results: 162 patients, 57% male, mean age 29.3 years (17 to 69) completed the questionnaire. 57% were currently employed (31% full-time, 22% part-time). The level of qualifications achieved and FEV₁ were significantly related to employment status, although the variance explained was small ($R^2 = 0.216$).

Table 1. Logistic regression analysis

Variable	p-value
Age	not significant
Highest qualification	0.000
FEV1	0.022
Socio-economic status	not significant

Perception of the impact of CF on employment was significantly related to socio-economic status (p=0.032), current lung function (p<0.01) and perception of the impact of disease on their education (p<0.01).

Conclusions: Employment figures are currently disappointing, and appear to be affected by educational achievement and health status. Previous studies have shown a link between employment, quality of life and mental health. Career guidance and support in education should be an essential part of CF care.

326 Education and employment in CF: education experiences

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Objectives: Treatment advances in CF have resulted in improved health in children and young people, and an expectation that educational achievement will be less disrupted. This survey explored education experiences in one adult CF unit.

Methods: All adult patients attending the Leeds CF unit were asked to complete a questionnaire about their education, qualifications, and perceptions of the impact of their CF. Medical records were reviewed to obtain current FEV₁ and BMI, and socio-economic status calculated using postcodes.

Results: 162 patients, 57% male, mean age 29.3 years (range 17 to 69 yrs) completed the questionnaire. 93 of the participants (60%) left school before they were 18. There was a significant effect for social class ($t(154)=2.88$, $p<0.001$), but no relationship with current age or FEV₁. 42 participants (27%) gained a degree, less than the figure for the UK population, which has been between 35–39% since 2000 (OECD, 2008). There was again a significant effect for social class, ($t(149)=2.97$, $p<0.01$), but no relationship with current age or FEV₁.

Perception of the impact of CF on education was bimodally distributed and significantly related to perception of the impact on employment (p<0.01) and socio-economic status (p≤0.05). It was not related to school leaving age or university education.

Conclusions: Educational attainment remains a concern in CF, with important consequences for employment and quality of life. Although the reasons are not clear, advice and support at all stages of education is important.

328 Pregnancy- and motherhood experiences in 23 Danish women with cystic fibrosis

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Background: As a result of improved treatment CF patients live longer into adulthood, and women with CF reach reproductive age and become mothers.

Aim: To review experience and outcome from Copenhagen CF Centre and evaluate if the support from the CF team could be better.

Method: 23 Danish women with CF, pregnant in the period 1990–2010, participated in the study. Data were collected from our database and telephone interviews. Data were: baseline demographics, breast- or bottlefeeding, educational and employment status.

Results: 23 women gave birth to 28 children with an average age at delivery of 25.7 yrs. Mean weight gain during pregnancy was 7.5 kg, mean BMI rose from 21.1 to 23.9. Mean birth weight 2.82 kg, mean gestational age was 37 weeks. 14 children were breastfed, 11 bottlefed and 3 unknown. 8 women suffered from CFRD, 3 got gestational diabetes and 12 did not have any of these. 11 women increased FEV₁ by 8.6% during pregnancy while 12 women decreased by 8.8%. The ones who gained less than 10 kg had the largest decrease in FEV₁ by 12.04%. 2 years after birth 9 women had a significant decrease in FEV₁ by 9.1%. 1/2 of the women had 3 yrs education and the rest had either a short or long education. A trend is that more mothers with CF receive early retirement pension or had flexjob than healthy mothers.

Conclusion: The children have a lower birthweight and gestational age than babies of healthy mothers. Weight gain during pregnancy is less than recommended and they have difficulties breastfeeding. The decrease in FEV₁ seems to be connected with a lower weight gain. Counselling and multidisciplinary team input are important to optimize the outcome for mother and baby.